Key lessons learned from the INDIGO global network on mental health related stigma and discrimination

Article (Accepted Version)

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Stigmatization of people with mental illness can contribute to adverse consequences including: poor access to mental and physical health care; reduced life expectancy; exclusion from higher education and employment; increased risk of contact with the criminal justice system; victimization; poverty and homelessness[1].

The WPA Open the Doors programme was initiated by one of us (NS) in 1999 and included both action and research components in 23 countries worldwide. This work led to the creation of the WPA Stigma Section, and to establishing a series of biannual international stigma related conferences, entitled *Together Against Stigma*.

We subsequently created the INDIGO (International Study of Discrimination and Stigma Outcomes) Research Network to undertake research related to stigma and discrimination (http://www.indigo-group.org/). Here we summarize the work of the INDIGO network over the last decade, and set out what we have learned.

In the first phase, colleagues in 27 countries worldwide agreed to join the network, and we realized that no suitable scales existed to measure mental illness related discrimination. We therefore created the Discrimination and Stigma Scale (DISC), which was found to have strong psychometric properties[2]. Since 2012, the DISC-12 scale has been accessed by 216 research users in 55 countries worldwide.

In our first global stigma project, the DISC-12 scale was used to interview 729 people with a clinical diagnosis of schizophrenia across 27 countries. The results showed that over 90% had experienced discrimination because of their mental health status[3]. Most people (72%) reported a need to conceal their diagnosis. The results confirmed the universality of discrimination adversely affecting people with schizophrenia.

We next assessed 1,082 people with major depressive disorder in 35 countries, and found that 79% reported experiencing discrimination in at least one life domain. In exploring the data further, we unexpectedly found higher levels of experienced discrimination in high-income compared with middle- and low-income countries (LMIC)[4].

We conceptualized stigma in relation to its three components of knowledge, attitudes and behaviour. We therefore created and psychometrically tested the following toolkit of scales and measures across those domains, to be freely available to researchers worldwide:

- The Barriers to Access to Care Scale (BACE)[5], formulated following a systematic review of barriers to help-seeking.
- The Costs of Discrimination Assessment (CODA), assessing the costs related to mental illness related discrimination[6].
- The short version of the DISC-12 (DISCUS) scale, with strong psychometric properties and comparable reliability and validity to the original scale.
- The Mental Health Knowledge Schedule (MAKS), assessing factual items related to mental health[7].
- The Mental Illness: Clinicians' Attitudes (MICA) scales, evaluating attitudes among health care professionals or medical students towards people with mental illness[8].
- The Questionnaire of Anticipated Discrimination, exploring future expectation of discrimination (QUAD)[9].
- The Reported and Intended Behaviour Scale (RIBS), a short measure of the above domains[10].

These scales have been designed for global and open access use. They can be translated into any language, provided that each translation is copied to the repository at King's College London, to be freely available for other researchers. Up to now, the INDIGO scales have been

translated into a total of 31 languages. They have been used in 67 countries during the last five years. The scales are available on request (maria.milenova@kcl.ac.uk).

Following the toolkit phase of work, we more directly focused upon intervention studies. We produced a narrative and a systematic review of the global literature on interventions to reduce stigma and discrimination[1] and a paper on intervention studies in LMICs.

Taken as a whole, these reviews establish that: a) social contact (i.e., interpersonal contact between people with and without experience of mental illness) is the strongest proven active ingredient to reduce mental illness related stigma and discrimination; b) such social contact is most effective in educational settings for young people; c) there is emerging evidence that virtual/social media contact may be as effective as direct face-to-face contact; and d) there is a research gap on all of these issues in LMICs.

Since the INDIGO network was established, we have learned the following lessons on how a network may become successful, productive and sustainable.

- *Clear ground rules* are vital in terms of what are the role and responsibilities of all partners.
- *Establishing a learning collaborative*: we actively encourage sites to support each other, particularly in similar language or resource-level settings.
- *Taking a long-term view for sustainable capacity building*: for an international research network to survive, let alone thrive, it is necessary to purposively support early- and mid-career academic staff**.**
- *A distributed model of leadership for shared responsibilities and co-operation*: we have found it useful to distribute specific roles into discrete work packages, and to establish task teams for each of these tasks.
- *Freedom within a framework*: the coordinating centre agrees with project staff what their ultimate products or deliverables will be, when they will be delivered, and the intermediate steps, or milestones that will have to be completed to a given set of time points.
- *Multidisciplinary approach to research*: the network provides a unique resource for the development of new research in the field of stigma by bringing a variety of inter-disciplinary skills.
- *Regular communication*: it is vital to build a sense of belonging to a valued group of colleagues, and to celebrate intermediate as well as final project successes.

From our work in the INDIGO network so far, we have learned that stigma and discrimination are universal, that they are reversible, and that there are some variations in their manifestations across cultures. We continue to welcome colleagues who wish to join this network, and we are now considering how the learning generated by the network may be used to counteract stigma in other arenas.

Graham Thornicroft[1], Ioannis Bakolis[1], Sara Evans-Lacko[1,2], Petra C. Gronholm[1,2], Claire Henderson[1], Brandon A. Kohrt[3], Mirja Koschorke[1], Maria Milenova[1], Maya Semrau[1,4], Nicole Votruba[1], Norman Sartorius[5]

[1]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK; [2]Personal Social Services Research Unit, London School of Economics and Political Science, London, UK; [3]Department of Psychiatry, George Washington University, Washington, DC, USA; [4]Global Health and Infection Department, Brighton and Sussex Medical School, Brighton, UK; [5]Association for the Improvement of Mental Health Programmes, Geneva, Switzerland

G. Thornicroft is supported by the European Union Seventh Framework Programme (FP7/2007-2013) Emerald project. This paper is an output of the PRogramme for Improving Mental health carE (PRIME). The research was supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care South London at King's College London Foundation

Trust. The views expressed are those of the authors and not necessarily those of the UK National Health Service, the NIHR or the UK Department of Health.

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